

My name is Steven Cohen, and I am a disability self-advocate. In the interest of consolidation, my comments will address the presentation which has been scheduled for this afternoon on school counselors. In the event questions arise based upon my comments, and my calendar does not permit juggling trips to Grant Sawyer on short notice, I am always more than happy to address questions offline at (702) 688-9145 and/or Steven.Cohen@Alumni.UNLV.edu. In addition, I just booked my tentative round trip to the Capitol for Friday, March 29th last week.

In Summer 1998, my father took early retirement from a Controller-equivalent role in private industry. It was always his dream to relocate to Las Vegas. At that time in my life, we had known I was different than other age-appropriate children since preschool, but did not yet have a diagnostic criteria to associate my idiosyncratic behaviors with. Even with our realtor's wife being a member of the Clark County School District at that time, we did a thorough investigation of the District's resources, and ultimately determined that relocating from Central New Jersey to Southern would be a more appropriate decision at that time. It was there that I was formally diagnosed with Asperger's Syndrome, now known in the clinical manual as Autism Spectrum Disorder.

In the 5 years we spent in Southern New Jersey, the local police department ended up knowing us by name, because we were struggling to cope as a family with this new terminology, which continues to affect all of us almost 20 years later. During the first 3 years, I was verbally and physically aggressive toward those that were closest to me, my parents, attempted to self-harm, and came within inches of being institutionalized for "mental health" reasons.

As I entered high school, the disconnect from reality set in when my assigned social worker stated, "We had another Aspie, and they didn't do that," with that representing whatever "behaviors" I was experiencing at that moment in time. In lieu of suing that school district to provide a Free and Appropriate Education, or FAPE, as some educators may know it, on a baseball stadium trip, of all things, we were lucky to tour an alternative upper middle and high school environment in a suburb of St. Louis, where I ended up spending my junior and senior years. The month after I graduated with "good grades," as some schools justify getting out of their legal responsibilities with, we were finally able to realize my father's dream to move to Las Vegas.

Since relocating, with accommodations, I am proud to report to the Subcommittee that I graduated with a Bachelor's Degree in Accounting from UNLV in Fall 2016. I am currently exploring the possibility of returning to school for further education in Autism Spectrum Disorders, Intellectual and Developmental Disabilities, and/or Applied Behavior Analysis. Unfortunately, however, my attempts to "fit in" with mainstream society continue to be an issue, as recently as a month ago. Nationally, estimates are that 75% of working age people with Asperger's or another autism spectrum disorder are either unemployed or underemployed. I can only speak for Nevada's available Federally mandated social welfare programs, but, without one of the key indicators of a quality of life, competitive, integrated employment with people without disabilities, working aged people with Asperger's and on the autism spectrum are left to find other ways to occupy a 24-hour day. Unfortunately, with no 2 people with Asperger's or on the autism spectrum being identical, no "catch all" legislation will meet every family's needs. Unfortunately, without an appropriate quality of life, having been close to there ourselves, one of these needs often involves the criminal justice system. In every day life, many times, without the appropriate supports, such as family or close friends, people with Asperger's or autism spectrum disorder will provide a false sense of security regarding the subject matter being discussed, in that they will confirm understanding, when, in fact, they do not understand. In a criminal justice situation, I don't want to imagine the techniques that law enforcement officers have been trained to employ to ensure compliance. With the appropriate

training, people with Asperger's and autism spectrum disorder can live productive lives, free from the government's interference, whether in the social welfare or criminal justice context.

In conjunction with a work group, the pet projects I hope to realize during this session through Legislative and agency representative collaboration follow below. Some have come up in previous sessions, and/or have already been converted from BDR to either Assembly or Senate Bill for the upcoming session. Where appropriate, I have added a status parenthetical by each project, to allow senior Legislators an opportunity to locate or request historical information.

- 1) Functional cameras in special education classrooms, which can speak for those students with intellectual and/or developmental disabilities who may have limited functioning capabilities, and cannot say words to the effect of, "Parent, Johnny hurt me today, and here's why." (Currently SB 109)
- 2) Regular training for all personnel Statewide who may interact with people with autism spectrum disorder, as well as intellectual and developmental disabilities more broadly, as well as technological investments in ensuring that interactions with people with autism spectrum disorder, and intellectual and developmental disabilities more broadly, are as smooth as possible. For example, it has been my long-standing understanding that the Metropolitan Police Department's dispatch system is too old to allow for any autism spectrum disorder and/or intellectual and developmental disability information to be kept on file, for families who may regularly interact with law enforcement; by contrast, Northern Nevada has already been retaining this information for several years (School District training passed on party line vote in 2017 session)
- 3) An additional appropriation for the State to meet its Federal mandate to provide a free and appropriate education, or FAPE for short, to students with autism spectrum disorder, and intellectual and developmental disabilities more broadly
- 4) An additional appropriation for the Bureau of Vocational Rehabilitation, or BVR for short, to meet its Federal mandate to provide transition services from local public school systems to "real life"
- 5) State, city, and county employment opportunities for young adults with intellectual and/or developmental disabilities, known to consumers and Vocational Rehabilitation staff as the 700 Hour program, with a focus on customizing opportunities for young adults with autism spectrum disorder, and a thorough review of the State Personnel and related statutes to ensure that protections exist appropriately for protected Federal civil right class individuals, which would include candidates with intellectual and/or developmental disabilities, and a joint resolution urging Congress to end the business practice of sub-minimum wage environments, previously known to senior Legislators, people with intellectual and developmental disabilities, and service providers as sheltered workshops (700 Hour program is currently SB 50)
- 6) An additional appropriation for the Autism Court
- 7) A bill of rights related to the criminal justice system for people with Asperger's and autism spectrum disorder, as well as disabilities more broadly, including those persons who may not be able to communicate effectively

8) A quality assurance review of the case management models deployed by the Department of Health and Human Services and Vocational Rehab to determine whether duplicity exists, and whether agencies may be able to consolidate/share case management personnel, etc.

9) An increase in the Registered Behavior Technician and related Medicaid service reimbursement rates, to reduce the waiting list of families for early intervention through young adult Applied Behavior Analysis services; in addition, an additional expansion of the Autism Treatment Assistance Program funding, to permit for transitioning young adults from high school to “real life” to have a seamless transition from ATAP case management to Vocational Rehab and/or the geographically-appropriate Regional Center (Discussion has been occurring at least since 2014)

10) A livable minimum wage for direct support professionals who are certified through an agency, and largely paid by the geographically-appropriate Regional Center and/or Medicaid to provide independence skill development services to young adults with intellectual and/or developmental disabilities and/or an increase in the related reimbursement rate

11) A quality assurance review of the home and community based waiver, supportive living, and jobs and day training programs largely jointly funded by the geographically-appropriate Regional Center and/or Medicaid to ensure community integration for desiring individuals, pursuant to the Federal Olmstead vs. L.C. decision from the early 2000's, as well as a joint resolution urging Congress to permit people with intellectual and developmental disabilities to exercise the same rights as people without intellectual and developmental disabilities, without risking their benefit eligibility (e.g., marriage)

12) An appropriation to continue the Money Follows the Person program operations, as well as transitioning its positions from grant-funded to State-funded (Concept currently continued for 3 months by recent Congressional vote; status beyond 3 months unclear due to recently-suspended Federal shutdown)

People with autism spectrum disorder, as well as intellectual and developmental disabilities, are people first. Thank you for your consideration, and I look forward to working with relevant parties during session to realize or advance each of the goals outlined on or before June 3rd, plus the statutorily permissible time for the Governor to review bills passed at the last minute. Some of these subjects have been passed previously, but need improvement and/or protection, and some are new. I hope that these subjects have been informative to the Committee, as well as the Legislature as a whole, and that these subjects will receive due consideration during session.